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Hernández-Padilla, José Manuel ORCID logoORCID: <https://orcid.org/0000-0002-5032-9440>,
Correa-Casado, Matías, Granero-Molina, José, Cortés-Rodríguez, Alda Elena, Matarín
Jimenez, Tamara María and Fernández-Sola, Cayetano (2019) Psychometric evaluation and
cultural adaptation of the Spanish version of the “Scale for End-of Life Caregiving Appraisal”.
Palliative and Supportive Care, 17 (3) . pp. 314-321. ISSN 1478-9515 [Article]
(doi:10.1017/S1478951518000470)

Final accepted version (with author's formatting)

This version is available at: <https://eprints.mdx.ac.uk/25295/>

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Title

Psychometric evaluation and cultural adaptation of the Spanish version of the ‘Scale for End-of Life Caregiving Appraisal’.

Authors’ names and affiliations

José Manuel Hernández-Padilla¹⁻², Matías Correa-Casado³, José Granero-Molina²⁻⁴, Alda Elena Cortés-Rodríguez², Tamara María Matarín-Jiménez⁵, Cayetano Fernández-Sola²⁻⁴

¹Adult, Child and Midwifery Department. School of Health and Education. Middlesex University. Hendon Campus. The Burroughs. NW4 4BT. London. United Kingdom.

²Nursing, Physiotherapy and Medicine Department. Faculty of Health Sciences. University of Almeria. Spain. Postal address: Universidad de Almería. Edificio de Ciencias de la Salud. Carretera de Sacramento s/n. Almería. Postcode: 04120. Spain.

³Internal medicine ward at Poniente Hospital. Carretera de Almerimar 31. Postcode: 04700. El Ejido. Almería. Spain.

⁴Associate Researcher. Faculty of Health Sciences. Universidad Autónoma de Chile. Temuco. Chile.

⁵Internal medicine ward at Motril Hospital. Av. Enrique Martín Cuevas s/n. Postcode: 18600. Motril. Granada. Spain.

Corresponding author

Dr. José Manuel Hernández-Padilla.

Postal address: Universidad de Almería. Edificio de Ciencias de la Salud. Carretera de Sacramento s/n. Almería. Postcode: 04120. Spain.

Email address: J.Hernandez-Padilla@ual.es

Title

Psychometric evaluation and cultural adaptation of the Spanish version of the ‘Scale for End-of Life Caregiving Appraisal’.

Abstract

Objective: To translate, culturally adapt and psychometrically evaluate the Spanish version of the ‘Scale for End-of Life Caregiving Appraisal’ (SEOLCAS).

Methods: Observational cross-sectional study. Convenience sample of 201 informal end-of-life caregivers recruited in a southern Spanish hospital. The reliability of the questionnaire was assessed through its internal consistency (Cronbach’s α) and temporal stability (Pearson’s correlation coefficient (r) between test-retest). The content validity index of the items ($I-CVI$) and the scale ($S-CVI/Ave$) was calculated. Its criterion validity was explored through performing a linear regression analysis to evaluate the SEOLCAS’ predictive validity. Exploratory factor analysis was used to examine its construct validity.

Results: The SEOLCAS’s reliability was very high (Cronbach’s $\alpha=0.92$). Its content validity was excellent (all items’ *content validity index*=0.8–1; *scale’s validity index*=0.88). Evidence of the SEOLCAS’ criterion validity showed that the participants’ scores on the SEOLCAS explained approximately 79.3% of the between-subject variation of their results on the Zarit Burden Interview. Exploratory factor analysis provided evidence of the SEOLCAS’ construct validity. This analysis revealed that two factors (‘internal contingencies’ and ‘external contingencies’) explained 53.77% of the total variance found and reflected the stoic Hispanic attitude towards adversity.

Significance of the results: The Spanish version of the ‘Scale for End-of Life Caregiving Appraisal’ has shown to be an easily-applicable, valid, reliable and culturally-appropriate tool to measure the impact of end-of-life care provision on Hispanic informal caregivers. This tool offers healthcare professionals the opportunity to easily explore Hispanic informal end-of-life caregivers’ experiences and discover the type of support they may need (instrumental or emotional) even when there are communicational and organisational constraints.

Keywords

Palliative care; end of life care; carers; family caregivers; questionnaire design; psychometrics.

Introduction

International literature suggests that patients with far-advanced diseases often prefer to receive end-of-life care and die at home (MacArtney et al., 2016; Woodman et al., 2016; Wright et al., 2016). The provision of end-of-life care at home is a complex endeavour that would not be possible without the informal caregivers' support (Nuño-Solinís et al., 2016). Informal caregivers are laypeople who play a close supportive role to patients, share in their illness experiences, and provide essential instrumental and emotional support for them (Gardiner et al., 2014). It is believed that the experience of providing end-of-life care at home can be burdensome and informal caregivers may experience difficulties in maintaining their own health and quality of life (Dalai & Bruera, 2017; MacArtney et al., 2016). For this reason, it is crucial that healthcare professionals explore informal end-of-life caregivers' experiences on an individual level so that their real health needs are identified and meaningful support is offered (Applebaum, 2017; Granero-Molina et al., 2016; Jack et al., 2015; Reblin et al. 2015; Reyniers et al., 2014; Robinson et al., 2017; van der Steen et al., 2014).

The assessment of informal end-of-life caregivers' needs and the provision of meaningful support are services offered by healthcare systems that have achieved advanced integration of palliative care within their mainstream service provision (Lynch et al., 2013). Unfortunately, this is not the case in many Spanish-speaking countries, where the provision of palliative care is not fully integrated into all levels of care (e.g. Spain, Argentina, Chile, and many more) (Lynch et al., 2013). In such contexts, informal end-of-life caregivers may have limited access to palliative care services and they are at risk of becoming 'invisible' to their healthcare systems (Lynch et al., 2013; Veloso & Tripodoro, 2016). In order to avoid this, and until full integration of palliative care into all levels of care is achieved in Spanish-speaking countries, it is necessary for all

healthcare professionals attending to end-of-life patients (irrespective of their work setting and whether they are palliative care specialists or not) to be able to explore the informal end-of-life caregivers' experiences so that their needs can be identified and the appropriate support can be provided (Fernández-Sola et al., 2017). This could be done *ad hoc*, for example, when informal caregivers accompany the end-of-life patient to hospital admissions or to community-based consultations (Fernández-Sola et al., 2017; Rocque et al., 2013). However, evidence suggests that healthcare professionals who are non-specialists in palliative care often lack competence to manage emotionally-charged conversations and have limited time available to effectively explore informal end-of-life caregivers' experiences (Adams et al., 2011; Bloomer et al., 2013; Caswell et al., 2015; Gagnon & Duggleby, 2014; Robinson et al., 2014; Smith et al., 2009; Willard & Luker, 2006). In order to overcome such barriers, these healthcare professionals could use standardised and culturally-adapted psychometric instruments that would allow them to quickly assess the informal end-of-life caregivers' experiences without having to have a difficult conversation for which they may not be prepared.

To the best of our knowledge, most of the psychometric instruments that are available to explore informal end-of-life caregivers' experiences focus on assessing only one particular dimension of end-of-life caregiving such as self-efficacy (Porter et al., 2008), burden (Dumont et al., 2008; Higginson et al., 2010) or comfort (Novak et al., 2001). Consequently, they would not allow healthcare professionals to easily and quickly explore the experience of informal end-of-life caregivers as a whole using just one questionnaire. In this context, the 'Scale for End-of Life Caregiving Appraisal' (EOLCAS) emerges as a useful instrument in so far as it comprehensively assesses the experience of end-of-life caregivers in four domains: 'physical suffering', 'caregiving burden', 'positive caregiving appraisal' and 'social support pursuit' (Lee et al., 2010).

Using the EOLCAS as a tool to explore informal end-of-life caregivers' experiences would allow healthcare professionals in any type of setting to better understand individuals' subjective responses to potential stressors and identify whether their coping mechanisms actually help them to maintain a healthy biopsychosocial balance (Lee et al., 2010). However, only an English version of the EOLCAS (validated amongst a Korean sample) has been published (Lee et al., 2010). The translation, cultural adaptation and validation of its Spanish version would allow healthcare professionals to explore the experience of Spanish-speaking informal end-of-life caregivers worldwide.

The aim of this study was to translate, culturally adapt and psychometrically evaluate the Spanish version of the 'Scale for End-of Life Caregiving Appraisal'.

Methods

Study design and participants

An observational cross-sectional design guided this study. The pilot and main study samples were recruited using the same convenience sampling method. Individuals who attended the internal medicine ward in a general southern Spanish hospital between April 2015 and May 2016 were formally invited to participate in the study if they met the following inclusion criteria: [1] to be ≥ 18 years old, [2] to be the main informal caregiver for a patient with a far-advanced disease, [3] to not suffer any cognitive impairment that could interfere with the understanding and completion of the scale. A total sample of 201 individuals volunteered to participate and their demographics were collected (age, gender, occupation, relation to the patient, household income, level of education completed, and time as main informal caregiver).

Ethical considerations

The institutional 'Research Ethics Committee' granted ethical approval before initiating the data collection (TE_15_34). All individuals fulfilling the eligibility criteria

were invited to participate and given a written document with information about the participants' rights, the study's aim and the data collection process. Volunteer participants signed an informed consent form before participating. The collected data were treated according to the current European legislation on data protection (Directive 95/46/EC, 1995).

Translation, cultural adaptation and pilot study of the SEOLCAS' initial version.

The English-to-Spanish translation of the EOLCAS was performed following a forward-backward procedure (Koller et al., 2007). Two independent bilingual experts (native Spanish, proficient in English) individually undertook an English-to-Spanish translation of the EOLCAS. Minor differences between both translators' versions were easily reconciled and a common initial Spanish version of the EOLCAS (i-SEOLCAS) was created. An independent bilingual translator (native English, proficient in Spanish) undertook a 'blind back-translation' of the i-SEOLCAS (Koller et al., 2007). Before initiating the pilot study, the researchers and a panel of 5 independent bilingual experts reviewed the English version of the original EOLCAS, the i-SEOLCAS and the 'blind back-translation'. It was unanimously agreed that the i-SEOLCAS fully respected the semantic and conceptual meanings of the original EOLCAS.

The i-SEOLCAS was critically revised by a panel of 15 independent experts in palliative care from 6 different institutions and was tested among a sample of 51 participants who only participated in the pilot study. The experts were asked to score each item as 1='not relevant', 2='somewhat relevant', 3='quite relevant' or 4='highly relevant' for evaluating the experience of informal end-of-life caregivers. Each item's content validity index (I-CVI) was calculated by adding the number of experts who rated each item as either 'quite relevant' or 'highly relevant' and dividing it by the total number of experts in the panel (Polit & Beck, 2006). An $I-CVI \geq 0.78$ is considered

acceptable when evaluated by 15 experts (Delgado-Rico et al., 2012; Polit & Beck, 2006); the items with an I-CVI<0.78 were removed from the i-SEOLCAS before piloting it.

To examine the i-SEOLCAS' reliability and temporal stability, the 51 participants comprising the pilot sample completed the scale on two different occasions separated by a 4-week interval. After assessing and corroborating that the variable followed a normal distribution, temporal stability of the i-SEOLCAS was examined by calculating Pearson's correlation coefficient (r) for the test-retest results. The i-SEOLCAS' reliability was assessed using the following three estimators: [1] scale's Cronbach's coefficient alpha (α), [2] items' corrected item-total correlation (C-ITC), [3] estimated α of the tool if a particular item was removed. Items were retained as part of the i-SEOLCAS if: [1] the instrument's α did not increase after removing that item and [2] item's C-ITC>0.3.

To explore the i-SEOLCAS' readability, understandability and cultural appropriateness, the experts and the participants were requested to provide feedback on whether they had any difficulties when reading or completing the scale. They were also encouraged to add any other items that could contribute to better exploring the experience of informal end-of-life caregivers.

The results of the content validity and reliability analysis are presented in Table 1. Before administering the tool to the pilot sample, items 2, 8, 13, 21 and 24 were removed from the i-SEOLCAS as the experts considered they were redundant and agreed that they were not relevant in measuring the experience of informal end-of-life caregivers in the context of the study (all I-CVI<0.78). Then, the 27-item pilot version of the SEOLCAS (p-SEOLCAS) was tested amongst the pilot sample ($N=51$) and although it evidenced an excellent temporal stability ($r=0.87$; $p<0.001$), its internal

consistency was not sufficiently strong ($\alpha=0.76$). As Table 1 shows, items 3, 9-15, 18-19 and 29-32 did not meet the criteria to remain part of the SEOLCAS. Furthermore, all of these items received negative comments about their appropriateness to measure the experience of providing informal end-of-life care from both the experts and participants. Therefore, they were all removed from the already-piloted SEOLCAS version. After this, the 14-item SEOLCAS evidenced an $\alpha=0.91$ and all its items' C-ITC >0.3 . Lastly, neither the experts nor the participants in the pilot study reported any issues reading or understanding the SEOLCAS and did not recommend adding any items. Consequently, no changes in the scale were needed.

Table 1.

Results of the content validity and internal consistency analysis of the i-SEOLCAS.

| | I-CVI [†] | i-SEOLCAS [*] Cronbach's α if item deleted | C-ITC [‡] |
|--|--------------------|--|--------------------|
| 1. I feel fatigue while caring for the patient. | .87 | .74 | .79 |
| 2. I have sleep disturbance while caring for my patient. | .47 | Removed before pilot study | |
| 3. I have experienced a role change (e.g., job) while caring for the patient.* | .73 | .78 | .24 |
| 4. I have limited time for myself while caring for the patient. | .93 | .76 | .51 |
| 5. I have limited social relationships (e.g. meeting friends) when caring for the patient. | .93 | .77 | .39 |
| 6. I feel my health has got worse while caring for the patient. | 1 | .75 | .63 |
| 7. I have a financial burden (e.g. decreased household income) while caring for the patient. | .80 | .76 | .42 |
| 8. I have indigestion while caring for the patient.* | .53 | Removed before pilot study | |
| 9. I feel I have grown personally while caring for the patient.* | .80 | .79 | -.11 |
| 10. I appreciate my life while caring for the patient.* | .80 | .79 | -.19 |
| 11. I appreciate my formal and informal support networks (e.g. religion, friends).* | .80 | .79 | -.05 |
| 12. I have a better relationship with the patient while caring for him/her.* | .80 | .79 | -.10 |
| 13. I feel good that I can do something for the patient.* | .47 | Removed before pilot study | |
| 14. I have a better relationship with other family members while caring for the patient.* | .80 | .79 | -.18 |
| 15. I need guidance for my caregiver role.* | .93 | .77 | .24 |
| 16. I want to deny my role as a caregiver. | .93 | .76 | .41 |
| 17. I feel I am powerless. | 1 | .76 | .54 |
| 18. I worry about what will happen to my patient.* | .80 | .77 | .13 |
| 19. I feel grief/loss about losing my patient.* | .73 | .77 | .08 |
| 20. I feel depressed while caring for my patient. | .80 | .76 | .53 |
| 21. I regret for what I have been doing to my patient.* | .60 | Removed before pilot study | |
| 22. I feel strain/anxiety while caring for the patient. | .80 | .77 | .37 |

| | | | |
|--|-----|----------------------------|-----|
| 23. I feel intolerance while caring for the patient. | .80 | .77 | .38 |
| 24. I feel guilty while caring for the patient.* | .47 | Removed before pilot study | |
| 25. I need spiritual/emotional support. | .80 | .76 | .45 |
| 26. I feel loneliness while caring for the patient. | .93 | .76 | .50 |
| 27. I am exhausted with caring for the patient. | .80 | .75 | .65 |
| 28. I feel discomfort/uneasy while caring for the patient. | .87 | .76 | .51 |
| 29. I need useful resources (e.g. volunteers) while caring for the patient.* | .87 | .79 | .28 |
| 30. I want information about the patient's health status and how to care for the patient.* | .80 | .77 | .29 |
| 31. I need help regarding preparation for death and funeral services.* | .80 | .79 | .01 |
| 32. I feel uncertainty about my patient's future.* | .80 | .77 | .26 |

[†] I-CVI = Item Content Validity Index

[‡] C-ITC = Corrected Item-total Correlation

* Item did not meet the criteria to be retained as part of the SEOLCAS

Data analysis and psychometric evaluation of the SEOLCAS

The already-piloted 14-item version of the SEOLCAS (see Appendix 1) was administered to the main sample ($N=150$) and psychometrically tested following other authors' recommendations and guidelines (Coaley, 2014; Delgado-Rico et al., 2012; Hernández-Padilla et al., 2016; 2017; Polit & Beck, 2006). An independent statistician was consulted for advice on the data analysis strategy and IBM® SPSS® v.21 was used to perform the statistical analysis. The normality graphs (histograms and Q-Q plots), the Shapiro-Wilk test and the skewness & kurtosis z-values demonstrated that the observed variables were normally distributed. Linear regression analysis and exploratory factor analysis (EFA) were performed (see below for more details).

The grade level and overall readability of the SEOLCAS was evaluated using the Flesch-Kincaid tool in Microsoft Word® 2011. The scale's understandability was assessed by asking the participants to provide feedback about the difficulties they might have encountered when completing the SEOLCAS. The completion time for the SEOLCAS was also recorded.

The methodology that guided the evaluation of the SEOLCAS' reliability and content validity has already been described in the section 'Translation, cultural

adaptation and pilot study of the SEOLCAS' initial version'. Additionally, the scale's content validity index (S-CVI/Ave) was calculated and a result higher than 0.78 was interpreted as evidence of the SEOLCAS' ability to operationalize the experience of informal end-of-life caregivers as a measurable construct (Coaley, 2014; Delgado-Rico et al., 2012; Polit & Beck, 2006). The SEOLCAS' criterion validity was explored through the assessment of its predictive validity. In order to do so, the SEOLCAS' ability to predict the participants' caregiving burden was explored performing a linear regression analysis. The Zarit Burden Interview (ZBI) was used to measure participants' caregiving burden (Gort et al, 2005). Preliminary analyses were performed to ensure that there was no violation of assumption of normality and linearity. For the evaluation of the SEOLCAS' construct validity, an EFA using principal axis factoring (PAF) was undertaken. Firstly, the pertinence of carrying out EFA was tested by performing the Bartlett's Test of Sphericity and the Kaiser-Meyer-Olkin Measure of Sampling Adequacy. Then, a PAF with Varimax rotation was performed. Items were kept in a factor if they had a factor-loading value ≥ 0.45 (Tabachnick & Fidell, 2013). Factors were considered a structural part of the SEOLCAS if they met the following criteria: to have an eigenvalue ≥ 1 and to have a clear break in eigenvalues in the scree plot (Tabachnick & Fidell, 2013).

Scoring and interpretation system for the SEOLCAS

In order to facilitate the interpretation of the individuals' results on the SEOLCAS, an internal scoring system was developed. Firstly, the sample's mean score and its standard deviation (SD) were calculated. Then, the following three scoring categories

were developed: [1] scores >1 SD below the mean, [2] scores \leq 1 SD below or above the mean, and [3] scores >1 SD above the mean (Van de Broeck & Brestoff, 2013).

Results

Description of the main sample

Table 2 shows the main sample's demographics in detail. Participants' mean age was 55.69 years (SD=10.72; range=20-79) and 80% of the sample was female. The mean 'time being the main informal caregiver' for the patient was 5.42 months (SD=4.86; range=0.50-38).

Table 2.
Demographic characteristics of main sample

| | Main Sample (N=150) |
|----------------------------------|--|
| | <i>M</i> \pm <i>S.D.</i> |
| Age (years) | 55.69 \pm 10.72 |
| | <i>n</i> (%) |
| Gender | |
| Female | 120 (80.0) |
| Male | 30 (20.0) |
| Education level completed | |
| No formal education | 3 (2.0) |
| Primary education | 99 (66.0) |
| Secondary education | 18 (12.0) |
| Vocational education | 12 (8.0) |
| Higher education | 18 (12.0) |
| Relatedness to patient | |
| Spouse | 103 (68.7) |
| Children | 19 (12.7) |
| Other relatives | 28 (18.7) |
| Household income | |
| Preferred not to say | 50 (33.3) |
| Below average | 53 (35.3) |
| Average | 41 (27.3) |
| Above average | 6 (4.0) |
| Time as caregiver | |
| Less than 1 month | 11 (7.3) |
| 1-6 months | 101 (67.3) |
| 6-12 months | 32 (21.3) |
| More than 12 months | 6 (4.0) |

Psychometric properties of the SEOLCAS

The reading level of the SEOLCAS equates to 5th grade. None of the participants reported any difficulties when reading and completing the SEOLCAS. Moreover, the mean time of completion for the scale was less than 13 minutes (range=5-20 minutes).

The results for the SEOLCAS' internal consistency analysis are presented in Table 3. In summary, the SEOLCAS' $\alpha=0.92$ and this would not have increased after removing any of the items. The C-ITC for the 14 items ranged between 0.43-0.82.

Content validity analysis showed that the I-CVI for the 14 items comprising the SEOLCAS ranged from 0.80-1 (see Table 3) and the S-CVI/Ave=0.88. Predictive validity analysis showed a significant regression equation ($F(1,148)=567.69$; $p<0.001$) in which the participants' scores on the SEOLCAS explained 79.3% of the between-subject variation of their results on the ZBI. Participants' score on the ZBI is equal to $4.32+0.58$ points when their scores on the SEOLCAS are also measured in points. Participants' scores on the ZBI increased by 0.58 points for each point they obtained on the SEOLCAS. Construct validity analysis results are as follows. The Barlett's Test of Sphericity ($\chi^2=1164.51$; $p<0.001$) and the Kaiser-Meyer-Olkin measure of sampling adequacy ($KMO=0.91$) showed that it was appropriate to conduct an EFA. Table 4 summarises the results of the PAF on the 14-item SEOLCAS. Two factors presented eigenvalues ≥ 1 , a clear representation on the plot of eigenvalues, and all items with a factor-loading coefficient ≥ 0.45 . These two factors accounted for 53.77% of the total variance found and contribute to measure the extent to which either 'external contingencies' (Factor 1) or 'internal contingencies' (Factor 2) impact the informal end-of-life caregiver's experience in Hispanic culture (see Table 4).

Table 3.
Results of the content validity and internal consistency analysis of the SEOLCAS.

| | I-CVI [†] | i-SEOLCAS [‡] Cronbach's α if item deleted | C-ITC [‡] |
|---|--------------------|--|--------------------|
| 33. I feel fatigue while caring for the patient. | .87 | .91 | .73 |
| 34. I have limited time for myself while caring for the patient. | .93 | .91 | .58 |
| 35. I have limited social relationships (e.g. meeting friends) when caring for the patient. | .93 | .91 | .59 |
| 36. I feel my health has got worse while caring for the patient. | 1 | .91 | .68 |

| | | | |
|---|-----|-----|-----|
| 37. I have a financial burden (e.g. decreased household income) while caring for the patient. | .80 | .92 | .43 |
| 38. I want to deny my role as a caregiver. | .93 | .92 | .48 |
| 39. I feel I am powerless. | 1 | .91 | .71 |
| 40. I feel depressed while caring for my patient. | .80 | .91 | .71 |
| 41. I feel strain/anxiety while caring for the patient. | .80 | .91 | .72 |
| 42. I feel intolerance while caring for the patient. | .80 | .91 | .61 |
| 43. I need spiritual/emotional support. | .87 | .91 | .64 |
| 44. I feel loneliness while caring for the patient. | .80 | .91 | .64 |
| 45. I am exhausted with caring for the patient. | .93 | .91 | .82 |
| 46. I feel discomfort/uneasy caring for the patient | .80 | .91 | .58 |

[†] I-CVI = Item Content Validity Index

[‡] C-ITC = Corrected Item-total Correlation

Scoring and interpretation system for the SEOLCAS

The scoring system developed allows for the interpretation of the participants' results on the total SEOLCAS and its two subscales. Firstly, the mean score on the total SEOLCAS was 28.99 and the SD was ± 11.09 . Consequently, the following three scoring categories were created for the interpretation of the participants' results on the total SEOLCAS: 'low impact'=0-17 points (scores >1 SD below the mean); 'moderate impact'=18-40 points (scores ≤ 1 SD below or above the mean); and 'high impact'=41-56 points (scores >1 SD above the mean). Secondly, the mean score on the 'external contingencies' subscale was 16.80 and the SD was ± 5.98 . Therefore, the following three scoring categories were created for the interpretation of the participants' results on the 'external contingencies' subscale: 'low impact'=0-10 points (scores >1 SD below the mean); 'moderate impact'=11-23 points (scores ≤ 1 SD below or above the mean); and 'high impact'=24-28 points (scores >1 SD above the mean). Thirdly, the mean score on the 'internal contingencies' subscale was 12.19 and the SD was ± 6.08 . Accordingly, the following three scoring categories were created for the interpretation of the participants' results on the 'internal contingencies' subscale: 'low impact'=0-5 points

(scores >1 SD below the mean); ‘moderate impact’=6-18 points (scores ≤1 SD below or above the mean); and ‘high impact’=19-28 points (scores >1 SD above the mean).

Table 4.

Factor loadings and total variance explained from the rotated factor structure of the SEOLCAS (*N*=150).

| Item by Factor | Factor | |
|--|--------|-------|
| | 1 | 2 |
| External contingencies | | |
| 1. I feel fatigue while caring for the patient. | .71 | .37 |
| 2. I have limited time for myself while caring for the patient. | .80 | .13 |
| 3. I have limited social relationships (e.g. meeting friends) when caring for the patient. | .71 | .19 |
| 4. I feel my health has got worse while caring for the patient. | .62 | .38 |
| 5. I have a financial burden (e.g. decreased household income) while caring for the patient. | .50 | .18 |
| 6. I feel loneliness while caring for the patient. | .52 | .37 |
| 7. I am exhausted with caring for the patient. | .69 | .42 |
| Internal contingencies | | |
| 8. I want to deny my role as a caregiver. | .17 | .65 |
| 9. I feel I am powerless. | .36 | .54 |
| 10. I feel depressed while caring for my patient. | .39 | .66 |
| 11. I feel strain/anxiety while caring for the patient. | .41 | .68 |
| 12. I feel intolerance while caring for the patient. | .28 | .73 |
| 13. I need spiritual/emotional support. | .37 | .48 |
| 14. I feel discomfort/uneasy caring for the patient | .19 | .68 |
| % of variance | 27.91 | 25.86 |
| Cumulative % of variance | 27.91 | 53.77 |

Discussion

Many Spanish-speaking countries have not achieved an advanced level of integration of palliative care into their mainstream service provision and informal end-of-life caregivers are at risk of becoming ‘invisible’ to healthcare systems (Lynch et al., 2013). For this reason and regardless of their speciality, level of expertise and work setting, all healthcare professionals in such contexts should use the encounters with end-of-life patients to also explore informal end-of-life caregivers’ experiences and discover their specific health needs (Fernández-Sola et al., 2017; Rocque et al., 2013). However, healthcare professionals’ ability to explore informal end-of-life caregivers’ experiences may be hampered by their lack of competence to conduct difficult conversations and/or their limited time availability (Adams et al., 2011; Bloomer et al., 2013; Caswell et al., 2015; Gagnon & Duggleby, 2014; Robinson et al., 2014; Smith et al., 2009; Willard & Luker, 2006). The use of valid and culturally-adapted psychometric instruments could help healthcare professionals with little or no knowledge of palliative care not only to overcome the aforementioned barriers but also to easily highlight those in need of extra support. This study aimed to translate, culturally adapt and psychometrically evaluate the Spanish version of the only already-published tool that assesses the experience of informal end-of-life caregivers as a whole: the ‘Scale for End-of Life Caregiving Appraisal’ (SEOLCAS) (Lee et al., 2010).

The psychometric analysis of the SEOLCAS focused on examining its ability to measure the construct ‘informal end-of-life caregiving experience’ (validity), its ability to accurately measure this construct (reliability), and its usability and cultural relevance (Coaley, 2014; Furr, 2014).

In order to explore the SEOLCAS’ ability to measure the construct ‘informal end-of-life caregiving experience’, its content, criterion and construct validity were assessed.

Regarding the instrument's content validity, the results from the review performed by the expert panel suggest that all the items included in the final 14-item version of the SEOLCAS contribute to operationalize 'informal end-of-life caregiving experience' as a measurable construct (Coaley, 2014; Furr, 2014; Hernández-Padilla et al., 2016; 2017). In terms of criterion validity, results have shown that the SEOLCAS can predict the informal end-of-life caregivers' burden. This can be seen as evidence of the SEOLCAS' ability to provide valid information about the experience of informal end-of-life caregivers (Coaley, 2014; Furr, 2014). Construct validity analysis has clearly shown that the SEOLCAS is comprised of two factors that represent different dimensions in the experience of Hispanic informal end-of-life caregivers. All these results evidence the SEOLCAS' ability to provide valid and specific information about the individual experiences of Hispanic informal end-of-life caregivers (Coaley, 2014; Furr, 2014; Hernández-Padilla et al., 2016; 2017). Complementing these psychometric properties, the SEOLCAS's internal consistency and its pilot version's temporal stability can be interpreted as strong indicators of the instrument's ability to measure this construct reliably (Coaley, 2014; Furr, 2014). Having a valid and reliable tool like the SEOLCAS would allow healthcare professionals to effectively explore the experiences and understand the needs of informal end-of-life caregivers without having to engage in emotionally-charged conversations that they may find difficult to manage (Caswell et al., 2015; Robinson et al., 2014; Willard & Luker, 2006). Additionally, evidence has shown that the SEOLCAS is very easy to understand and quick to complete; hence why it can be considered not only a valid and reliable instrument but also a usable one. Having an easily applicable tool like the SEOLCAS would help healthcare professionals to overcome a potential lack of time to explore the informal caregivers' experiences.

Whereas the original EOLCAS was comprised of 32 items and 4 dimensions that comprehensively assessed the experience of informal end-of-life caregivers as a whole (Lee et al., 2010), the SEOLCAS is only comprised of 14 items and 2 dimensions that mainly assess the impact of the experience on Hispanic informal end-of-life caregivers' lives. The result of this transformation could be explained by the well-documented influence of the stoic tradition on Hispanic culture (Benavente, 2013; de Ros & Omlor, 2017). In the stoic tradition, passions and emotions must be mitigated and life experiences are confronted with serenity (Nussbaum, 2009). This could explain why many items of the original EOLCAS did not meet the criteria to be kept as part of the SEOLCAS. Firstly, the experts considered that some items represented feelings that are very rarely associated with the experience of providing end-of-life care to a relative within Hispanic culture (see items 13, 21 and 24 in Table 1). Consequently, these items were removed from the questionnaire before its pilot study. Then, the participants' responses in the pilot study led to poor correlation between several items and the rest of the scale (see items 3, 9-12, 14 and 29-32 in Table 1). These results could reflect the stoic attitude towards adversity that is often attributed to Hispanic culture (Im et al., 2007; Scherz, 2017; Smith et al., 2009). Our participants were mostly middle-aged women who might accept their caregiver role as a moral obligation and not as a source of personal reward or extreme suffering (Scherz, 2017). The stoic tradition holds that virtue is in itself sufficient for happiness; it is only by rejecting what is external to the person ('external contingencies') and by cultivating reason as the ability to achieve appropriate judgements of our impressions ('internal contingencies') that virtue and, therefore, happiness can be attained (Becker, 2003; Nussbaum, 2009; Løkke, 2015). This philosophical construct is clearly reflected in the two factors that emerged from the SEOLCAS. The 'external contingencies' dimension includes all the items reflecting the

aspects of the caregiving experience that are external to one's virtue (i.e. money, friendship, physical health, social relationships, etc.). The 'internal contingencies' dimension includes all the aspects of the caregiving experience that are internal to the individual and therefore fully dependent on his/her ability to achieve appropriate judgements of his/her impressions (i.e. ability not to feel powerless, strained, anxious, etc.). Consequently, the SEOLCAS has the ability to not only measure the impact that providing end-of-life care has on Hispanic informal caregivers, but also to differentiate between the type of support that they may need depending on their scores. For example, information gathered from the dimension 'external contingencies' will indicate whether instrumental support may be needed and it can orientate the decisions or interventions that must be taken in order to offer the instrumental support an individual needs. Equally, the information gathered from the dimension 'internal contingencies' will indicate whether emotional support may be needed and it can orientate the decisions or interventions that must be taken in order to provide it.

Although the SEOLCAS has shown robust psychometric properties, some limitations must be highlighted. Firstly, having used a convenience sampling method limits the generalisation of the study's results. All participants were Spanish caregivers recruited from a single institution. This means that those willing to use the SEOLCAS amongst samples with radically different characteristics may need to undertake a validation study beforehand. Secondly, due to organisational constraints, the temporal stability of the SEOLCAS was only examined in its pilot version. It is important that future research tests the SEOLCAS' temporal stability using a larger sample of participants. Thirdly, the cultural adaptation and validation processes of the SEOLCAS have led to having an instrument with a narrower focus than the original one. Although the SEOLCAS can confidently assess the impact that providing end-of-life care has on

Hispanic informal caregivers and can differentiate between whether instrumental or emotional support may be needed, it is unclear as to whether its items and dimensions will suffice to understand how Hispanic informal end-of-life caregivers experience the phenomenon as a whole. Lastly, it is important to consider that our sample was predominantly middle-aged females and this may have impacted our results.

Conclusions

Although the SEOLCAS has a narrower focus than the original EOLCAS, its relevance remains unaffected. Following a rigorous validation test, the SEOLCAS has evidenced very good psychometric properties. The SEOLCAS has proven to be an easily-applicable, valid, reliable and culturally-appropriate instrument that can be used to explore the impact that the experience of providing end-of-life care has on Hispanic informal end-of-life caregivers. The SEOLCAS can enable healthcare professionals with little or no knowledge of palliative care to effectively explore the informal end-of-life caregivers' experiences regardless of their level of competence to manage emotionally-charged conversations or their time availability. All of this could contribute to discovering what the needs of Hispanic informal end-of-life caregivers may be so that appropriate support can be offered. We actively encourage healthcare professionals to use this tool in their clinical context (whichever this may be). This could be done *ad hoc*, for example, when informal caregivers accompany the end-of-life patient to hospital admissions or to community-based consultations. Furthermore, we also encourage healthcare professionals to develop specific local protocols that allow them to make appropriate decisions about the type of referrals and/or interventions that caregivers may need on the basis of their results on the SEOLCAS.

Acknowledgements

This research was supported by the Ministry of Economy and Competitiveness, Government of Spain (FFI2016-76927-P). The authors thank all the informal caregivers who voluntarily participated in this study and the authors of the original EOLCAS for giving us permission to use their tool.

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APPENDIX 1

Spanish version of the ‘Scale for End-of Life Caregiving Appraisal’

SEOLCAS[©]

Name of the authors

José Manuel Hernández-Padilla

Matías Correa-Casado

José Granero-Molina

Alda Elena Cortés-Rodríguez

Tamara María Matarín-Jiménez

Cayetano Fernández-Sola

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IMPORTANT NOTE

Please note that the ‘Scale for End-of Life Caregiving Appraisal’ (EOLCAS) was originally developed by Lee et al (2010). Although the original authors have given permission to culturally adapt and publish the Spanish version of the EOLCAS, the original EOLCAS cannot be entirely reproduced here.

Please, use the following reference to access the original English version of the EOLCAS:

Lee J, Yoo JS, Kim TH, Jeong JI, Chang SJ, Jung D. Development and validation of a scale for the end of life caregiving appraisal. *Asian Nurs Res* 2010; 4: 1-9. DOI: 10.1016/S1976-1317(10)60001-1.

| | | | |
|-------------------------------|--|---|--|
| Sexo | | Ingresos unidad familiar (mensuales) | |
| Edad | | Nivel de estudios | |
| Profesión | | Tiempo como cuidador | |
| Parentesco con el paciente | | | |

Versión en español de la escala evaluativa de la experiencia de cuidar al final de la vida (SEOLCAS)©

Gracias por participar en nuestra investigación.

Uno de nuestros objetivos es desarrollar y validar un cuestionario que nos ayude a entender mejor cómo es la experiencia de cuidar al final de la vida. Para ello necesitamos su ayuda.

Nos interesa conocer su grado de acuerdo con las afirmaciones que se le presentan más abajo. En este sentido, le pedimos que conteste honestamente y desde su punto de vista personal. No hay respuestas correctas o incorrectas. Sus opiniones y vivencias son todas válidas.

Para responder tendrá que marcar con una cruz una de la cinco opciones que se le presentan. ***Solo se permite señalar una opción para cada afirmación.***

Si tiene alguna duda o necesita ayuda para rellenar este cuestionario, no dude en preguntar a su enfermera y esta le ayudará encantado.

Por último, recuerde que su información será tratada con total confidencialidad.

1. Siento fatiga emocional y/o física mientras cuido del paciente.

| | | | | |
|---|---|---|--|--|
| 1 <input type="checkbox"/> Totalmente en desacuerdo | 2 <input type="checkbox"/> En desacuerdo | 3 <input type="checkbox"/> Ni de acuerdo ni en desacuerdo | 4 <input type="checkbox"/> De acuerdo | 5 <input type="checkbox"/> Totalmente de acuerdo |
|---|---|---|--|--|

2. Tengo poco tiempo para mí mismo/a mientras cuido del paciente.

| | | | | |
|---|---|---|--|--|
| 1 <input type="checkbox"/> Totalmente en desacuerdo | 2 <input type="checkbox"/> En desacuerdo | 3 <input type="checkbox"/> Ni de acuerdo ni en desacuerdo | 4 <input type="checkbox"/> De acuerdo | 5 <input type="checkbox"/> Totalmente de acuerdo |
|---|---|---|--|--|

3. Tengo relaciones sociales limitadas mientras cuido del paciente.

| | | | | |
|----------------------------|----------------------------|--------------------------------|----------------------------|----------------------------|
| 1 <input type="checkbox"/> | 2 <input type="checkbox"/> | 3 <input type="checkbox"/> | 4 <input type="checkbox"/> | 5 <input type="checkbox"/> |
| Totalmente en desacuerdo | En desacuerdo | Ni de acuerdo ni en desacuerdo | De acuerdo | Totalmente de acuerdo |

4. Siento que mi salud ha empeorado desde que cuido del paciente.

| | | | | |
|----------------------------|----------------------------|--------------------------------|----------------------------|----------------------------|
| 1 <input type="checkbox"/> | 2 <input type="checkbox"/> | 3 <input type="checkbox"/> | 4 <input type="checkbox"/> | 5 <input type="checkbox"/> |
| Totalmente en desacuerdo | En desacuerdo | Ni de acuerdo ni en desacuerdo | De acuerdo | Totalmente de acuerdo |

5. Cuidar del paciente supone una carga económica (por ejemplo, han disminuido los ingresos del hogar).

| | | | | |
|----------------------------|----------------------------|--------------------------------|----------------------------|----------------------------|
| 1 <input type="checkbox"/> | 2 <input type="checkbox"/> | 3 <input type="checkbox"/> | 4 <input type="checkbox"/> | 5 <input type="checkbox"/> |
| Totalmente en desacuerdo | En desacuerdo | Ni de acuerdo ni en desacuerdo | De acuerdo | Totalmente de acuerdo |

6. Me gustaría rechazar mi papel de cuidador.

| | | | | |
|----------------------------|----------------------------|--------------------------------|----------------------------|----------------------------|
| 1 <input type="checkbox"/> | 2 <input type="checkbox"/> | 3 <input type="checkbox"/> | 4 <input type="checkbox"/> | 5 <input type="checkbox"/> |
| Totalmente en desacuerdo | En desacuerdo | Ni de acuerdo ni en desacuerdo | De acuerdo | Totalmente de acuerdo |

7. Me siento impotente y sin fuerzas.

| | | | | |
|----------------------------|----------------------------|--------------------------------|----------------------------|----------------------------|
| 1 <input type="checkbox"/> | 2 <input type="checkbox"/> | 3 <input type="checkbox"/> | 4 <input type="checkbox"/> | 5 <input type="checkbox"/> |
| Totalmente en desacuerdo | En desacuerdo | Ni de acuerdo ni en desacuerdo | De acuerdo | Totalmente de acuerdo |

8. Me siento deprimido mientras cuido de mi paciente.

| | | | | |
|----------------------------|----------------------------|--------------------------------|----------------------------|----------------------------|
| 1 <input type="checkbox"/> | 2 <input type="checkbox"/> | 3 <input type="checkbox"/> | 4 <input type="checkbox"/> | 5 <input type="checkbox"/> |
| Totalmente en desacuerdo | En desacuerdo | Ni de acuerdo ni en desacuerdo | De acuerdo | Totalmente de acuerdo |

9. Siento tensión o ansiedad mientras cuido del paciente.

| | | | | |
|----------------------------|----------------------------|--------------------------------|----------------------------|----------------------------|
| 1 <input type="checkbox"/> | 2 <input type="checkbox"/> | 3 <input type="checkbox"/> | 4 <input type="checkbox"/> | 5 <input type="checkbox"/> |
| Totalmente en desacuerdo | En desacuerdo | Ni de acuerdo ni en desacuerdo | De acuerdo | Totalmente de acuerdo |

10. Me siento intolerante o intransigente mientras cuido del paciente.

| | | | | |
|----------------------------|----------------------------|--------------------------------|----------------------------|----------------------------|
| 1 <input type="checkbox"/> | 2 <input type="checkbox"/> | 3 <input type="checkbox"/> | 4 <input type="checkbox"/> | 5 <input type="checkbox"/> |
| Totalmente en desacuerdo | En desacuerdo | Ni de acuerdo ni en desacuerdo | De acuerdo | Totalmente de acuerdo |

11. Necesito apoyo emocional y/o espiritual.

| | | | | |
|----------------------------|----------------------------|--------------------------------|----------------------------|----------------------------|
| 1 <input type="checkbox"/> | 2 <input type="checkbox"/> | 3 <input type="checkbox"/> | 4 <input type="checkbox"/> | 5 <input type="checkbox"/> |
| Totalmente en desacuerdo | En desacuerdo | Ni de acuerdo ni en desacuerdo | De acuerdo | Totalmente de acuerdo |

12. Me siento sólo/a mientras cuido del paciente.

| | | | | |
|----------------------------|----------------------------|--------------------------------|----------------------------|----------------------------|
| 1 <input type="checkbox"/> | 2 <input type="checkbox"/> | 3 <input type="checkbox"/> | 4 <input type="checkbox"/> | 5 <input type="checkbox"/> |
| Totalmente en desacuerdo | En desacuerdo | Ni de acuerdo ni en desacuerdo | De acuerdo | Totalmente de acuerdo |

13. Estoy agotado/a mientras cuido del paciente.

| | | | | |
|----------------------------|----------------------------|--------------------------------|----------------------------|----------------------------|
| 1 <input type="checkbox"/> | 2 <input type="checkbox"/> | 3 <input type="checkbox"/> | 4 <input type="checkbox"/> | 5 <input type="checkbox"/> |
| Totalmente en desacuerdo | En desacuerdo | Ni de acuerdo ni en desacuerdo | De acuerdo | Totalmente de acuerdo |

14. Siento incomodidad o malestar mientras cuido del paciente.

| | | | | |
|----------------------------|----------------------------|--------------------------------|----------------------------|----------------------------|
| 1 <input type="checkbox"/> | 2 <input type="checkbox"/> | 3 <input type="checkbox"/> | 4 <input type="checkbox"/> | 5 <input type="checkbox"/> |
| Totalmente en desacuerdo | En desacuerdo | Ni de acuerdo ni en desacuerdo | De acuerdo | Totalmente de acuerdo |

Por favor use el siguiente recuadro para añadir cualquier comentario que desee sobre el cuestionario.

Gracias por su colaboración.

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José Manuel Hernández-Padilla
Lecturer in Nursing
Department of Nursing, Physiotherapy and Medicine
University of Almería
j.hernandez-padilla@ual.es